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The seven years of making the HP newsletter

The time has come to say goodbye after seven years and 15 issues of HP News. We took over after Ulla Nordensköld who had started the newsletter from scratch in the beginning of the decade. At the end of her period as the HP Chair, Jaana had applied for EULAR funding to make a printed newsletter and then became the editor of the News. Mikko started to coordinate the production of the HP News.

During the years we’ve had great professionals working with us. Our team has comprised two layout designers, Heikki Hjelt (2007 to 2009) and Heikki Luukkanen from 2010, two cartoonists, Fabrizio Scarpati, better known as Fabe (2007 to 2010), and Satu Cozens, as well as our language specialist, Virpi Pätsi, who has checked the grammar of each, and even this, for years now, the printing of the congress editions were trusted into the capable hands of Paavo Luostarinen at Alcon. Paavo will once again bring the fresh newsletters directly from the printer’s house to the Helsinki airport. But we could not have completed the newsletter without our devoted contributors, researchers, people with RMD, abstract winners, educational visit grant reporters, study group leaders, and HP member activists. They gave us the topics, newsflashes and intriguing insights of being a HP and the true spirit of interdisciplinary co-operation throughout Europe and beyond.

Under the HP leadership of Vice Presidents Peter Oesch, Käre Birger Hagen and Christina Opava, and chairs John Verhoef, Tanja Stammm, Thea Vliet Vlieland and Sue Oliver, the HP Committee has taken notable steps forward and it has been a pleasure to tell about HP breakthroughs in our own newsletter. We also thank EULAR for funding the newsletter and its continuity since the first printed edition was only meant to celebrate AHP Committee’s 20-year anniversary. We are also grateful for EULAR secretariat’s co-operation, support and flexibility at times when we have been able to act only on the last minute.

Once again to Paris
The first printed edition was introduced in Barcelona 2007. The Paris Congress in 2008 was the first time that we had our very own stand with specially-made banderols promoting the HP Committee. Back then there were four national HP associations as members of EULAR. Now when heading again to Paris, we have seventeen, soon eighteen, EULAR HP member societies.

The EULAR congresses have always worked as the main inspiration and vital way of finding themes to be published in HP News. That is the one time in a year, actually meet European colleagues and get faces to the numerous e-mails exchanged with committed HP delegates, HP Committee members, PARE, and EULAR Staff.

This will be the last time that Mikko packs his luggage filled with tools and a lot of tape to fix the HP stand and try to make sure that the newsletters and posters will arrive safely on the same flight from Finland.

We wish to thank you for these happy HP years. We hope that contributors all over Europe will continue to tell about their views on HP reality. It’s been fun. Keep up with the good work.

Jaana Hirvonen
Editor

Mikko Väisänen
Editorial assistant

EULAR Health Professionals News

Farewell
Well what can I say! We are delighted for Mikko and his new post as a director of human right association (Pikkaanma Set), but sad for us as we come to the end of an era. Mikko has been a strong, consistent and knowledgeable member of the EULAR HP team. He has guided new Chairs and Vice Presidents to key information and made us aware of all sort of important facts; such as potential timings and pitfalls when preparing the newsletter or working together to plan arrangements for our stand at Congress. His work alongside the editor of our newsletter Jaana have ensured that we have had always delivered a quality newsletter on time. That is despite having to cajole contributors and keep us all on track.

We will now be looking to the future and planning the provision of our future newsletters and support for our stand — but we would like to warmly thank both Mikko and Jaana for their excellent work over the years.

On behalf of all EULAR HPs a big thank you!

Sue Oliver
HP Chair

Greetings from the layout designer
I’d like to thank you, Mikko, warmly for the fruitful co-operation while making the HP News together. I will miss your carefully thought-through plans about the layout, the detailed ideas, and your positive attitude towards the work ahead. It’s been easy working with you.

Would you believe it — all these years and all the newsletters and projects done so far, we haven’t even once met in real life, everything has been sorted via e-mail and phone since we have quite a few hundred kilometres between us. Maybe one day we will meet. Meanwhile, good luck with your new commitments.

It has been fantastic to create the graphic image for the newsletter. I would like to thank everybody involved with the HP News for flexible and rewarding co-operation.

Best wishes

Heikki Luukkanen
HL-Mark/Layout designer
This is a special edition which will be in distribution at the EULAR Congress in Paris.

In this issue, we have an article by HP Vice president Christina Opava introducing the work of the HP Scientific sub-committee. HP Chair Sue Oliver invites you to the HP Congress stand at the EULAR village. Please notice the programme for the HP study groups available in this issue. Jana Korondova writes about the HP history from the Czech point of view and Jaana Hirvonen covers the latest on the national guidelines for the treatment of rare diseases. PARE’s Di Skingle tells about the campaign for constructive co-operation with health professionals. Agnes Kocher offered us an interesting report on her educational visit. We likewise have an US contribution on the dietician’s role in managing RMD.

Be sure to find out more about the plan for EULAR HP member directory, how to get a grant for an educational visit or for a research topic. Check also the HP scientific session themes at EULAR Congress 2014.

… to mention only a few items of this issue.

Hi there

I’m Kate Betteridge and I’m really looking forward to taking over the production of this newsletter. Thanks to Mikko and the team for the wonderful job they have done up till now.

I have been a supporter of EULAR for many years now, working in particular with EULAR PARE where I edit their newsletter Breakthrough and the Edgar Stené Prize booklet. I am also a member of the World Arthritis Day task group where I have been able to get to know your Vice President Christiana.

Last year, I was honoured to be asked to speak at your Highlight Session to share my three key themes from the PARE programme in 2013.

For many years, I worked for the UK charity Arthritis Care and edited their magazine Arthritis News, working with clinicians and health professionals to share developments in the treatment and management of rheumatoid and musculoskeletal diseases. Now my husband and I work together to improve outcomes for people living with long-term conditions by providing insight and advice on the patient perspective in service and policy planning.

I was diagnosed with adult form rheumatoid arthritis when I was 13 years old and it continues to significantly affect my life. I am a firm believer in working in partnership with my healthcare team and playing my part in managing my RA as well as I can.

I have had the pleasure of meeting a number of you over the years but I am looking forward to getting to know many more of you. I will be at the Congress in Paris so please say hello. I hope you will also get in touch with me throughout the year to let me know what you would like to see featured in your newsletter.

Best wishes
Kate
kate@katebetteridge.me.uk

EULAR HP News are available at http://www.eular.org/st_com_health_professionals.cfm

Since 2000, the HP Newsletter has functioned as the main information channel of health professionals in rheumatology within EULAR. The newsletter is published twice a year featuring the work of health professionals and all aspects of multidisciplinary collaboration.

Please give us tips about health professional thesis, projects, and new research themes in the musculoskeletal field. Contact the editor of newsletter for further information: kate@katebetteridge.me.uk.
Introducing HP Scientific Sub-committee at work

The Health Professionals’ (HP) Scientific Sub-committee is a distinguished working group of the Standing Committee for HPs. The members are actively involved in creating the scientific content of the annual congress HP program, including joint sessions with scientific and PARE, organised under the umbrella of EULAR’s official Scientific Programme Committee.

The Sub-committee has 12 members representing a good mix of countries, professions and seniority in research. Although the preparatory work for the congress with review of submitted abstracts for HP oral and poster presentations, of proposals for HP scientific sessions and workshops and of other related sessions is time consuming, the HP Scientific Sub-committee is also engaged in other HP missions inside EULAR such as review of research grant applications and supporting the strategic work to develop health professionals in rheumatology across Europe.

To be more inclusive
The new HP Scientific Sub-committee had its first meeting in Stockholm last December. A great deal of its discussions focused on the annual congresses. The wish to be more inclusive in identifying interesting topics, provide different session formats, and making congress material available to a wide range of European HPs was strong. One example was the suggestion to organise activities targeting first time HP visitors to the congress; another concerned the recognition of HPs at the opening ceremony. Activities to reach the HP tactical objectives of the EULAR 2017 objectives, i.e. to increase HP-led research projects with involvement of patients, to develop tailored materials and improve access to education of HPs, and to develop and implement a communication and PR strategy to address the needs of HPs, were also discussed.

Dissemination of knowledge
HP Vice president Christina H. Opava also highlights the value of HP study groups. – The multidisciplinary work that is of utmost importance in the care and rehabilitation of people with rheumatic and musculoskeletal diseases requires evidence-based contributions of each single professional group. It is thus very satisfying that study groups have been established in the past years and organize well attended activities at the yearly congresses, she says.

To foster the dissemination of knowledge, she hopes that a EULAR online course for health professionals, with shared modules as well as profession-specific ones, similar to the modules used by rheumatologists, will soon be available.

EULAR HP Structure

The HP abstracts for the Congresses are scored by the HP Sub-committee
EULAR’s Scientific Programme Committee is responsible for the Annual Congress. However, all the health professional abstract proposals for the EULAR Congress are reviewed by HP Scientific Sub-committee. This informal procedure was introduced to obtain a wide scope of themes and to receive more proposals from the HP research community. All HP session proposals are scored by the Sub-committee. Based on these scores, the official EULAR Congress Programme Committee suggests the submission of the proposals for the EULAR Steering Committee which makes the final approval of submission. Please find more about the Scientific HP program on page 19.

Members of the HP Scientific Committee
Christina Opava, PT, Sweden, HP Vice president
Susan Oliver, Nurse, UK, HP Chair
Thea Vliet Vlieland, Physician, Netherlands, Past HP chair
Annette Ladefoged de Thurah, Nurse, Denmark, Study group co-ordinator
Jo Adams, OT, UK
Ricardo Ferreira, Nurse, Portugal
Rinie Geenen, Psychologist, Netherlands
Anthony Redmond, Podiatrist, UK
Michaela Stoffel, OT, Austria
Rikke Helene Moe, PT, Norway
Yvonne van Eijk Hustings, Nurse, Netherlands
Thijs Swinnen, PT, Belgium

You can read Christina H. Opava’s interview in the EULAR HP News issue 2/2013.

Prof. Anthony Redmond’s nomination as the chair-elect 2014 to 2015 of the EULAR Standing Committee for Health Professionals will be subject for ratification at EULAR General Assembly in Paris.
The EULAR Standing Committee of Health Professionals in Rheumatology (ESCHPR) has set up three Sub-Committees called the Scientific Sub-committee, Educational Sub-committee, and Communication Sub-committee to carry out its tasks and duties.

Standing Committee of Health Professionals in Rheumatology has set up three Sub-Committees called the Scientific Sub-committee, Educational Sub-committee, and Communication Sub-committee to carry out its tasks and duties.

At the HP committee
- We endorse inter-/multidisciplinary collaboration in the treatment of RMD.
- Our HP Committee is a European platform for cooperation and shared information among the different health professionals working with rheumatology.
- We encourage health professional research in rheumatic and musculoskeletal diseases and work also to improve the patient’s role as the key expert of his/her own treatment.
- We wish to mainstream the best guidelines of care that help HPs in their work.
- We organise the HP scientific programme for EULAR congresses. Let us know about your HP project or research that could be useful for all HPs.
- We welcome you to the HP congress sessions, study groups, and poster tours.
- We also invite you to contribute to our newsletter on your national HP themes.
The time has come again for our Annual Congress and I know many of you are looking forward to visiting Paris with all its magic and romance! It will be a very busy congress for the HP Standing Committee but we are excited and looking forward to greeting you all. Do come along to our HP Stand no. H08–H09 and get to meet others, new members of national HP societies, members of the HP study groups or HP scientific sub-committee – many people pop to the stand and use it as a great networking opportunity.

The HP stand, located in the EULAR Village, provides a chance for Christina, Thea, Annette and me to visit in between all the meetings and sessions to hear your views and hopes. We really need to keep in touch with all of you to know how best to direct the work and activities of the EULAR HP program. I hope you have been receiving news from us on a regular basis, either through our website, study group communications or the newsletter. If not, do let us know when you come to the stand and we can find ways to keep you in touch!

As soon as the Congress program finishes, the EULAR Committees start the preparation towards the next Congress so we are already starting to look ahead to Rome in 2015. We have circulated our call for session proposals for 2015 and if you have some ideas about what you would really like to see in the program, please do see us on the stand or email myself: sue@susanoliver.com or Christina: Christina.Opava@ki.se. Equally, Annette is responsible for Study Groups and she will be around too – her email is: annethur@rm.dk.

Take part in the HP study groups

The HP study groups are established networks in their respective health professional disciplines. The groups play an active part in the research and treatment of rheumatic and musculoskeletal diseases. Please see the study group program on the next page and take advantage of this possibility to meet colleagues.

The benefits of the study groups for HPs:

• The work undertaken by each group is reported to the Executive Committee meetings raising the profile of HPs and the work we are undertaking in different ways.
• Ensure that we can request a meeting room at each Congress and be able to plan for this within the program.
• Provide an introduction to new attendees of EULAR who have an interest in the Study Group to be able to attend and possibly join the group.
• Enable the lead of the Study Group to hold a register of members and have an improved network of contacts.
• Offer the HP Scientific Sub-Committee another route for gaining expert advice from the Study Groups.
• Provide an opportunity for Study Group members to engage more with the work of EULAR.

Sue Oliver
Chair of the HP Committee

The number of the HP Stand is H08–H09 at the EULAR Village.

You can use the HP Stand as a meeting point. Check who is there during HP session and study group breaks.
The psychologists had a fruitful study group in Madrid.

Annette Ladefoged de Thurah is the coordinator for the Study Groups. She is a nurse by training and has a Master's Degree in Public health (MPH) and a Ph.D. from the University of Aarhus, Denmark. She has been working within rheumatology for almost twenty years. In recent years, she has been affiliated with the Department of Rheumatology, Aarhus University Hospital as a senior researcher. During the last years, Annette has been the deputy chairman in Danish Interdisciplinary Rheumatology Forum. (DIRF), the EULAR HP member association group in Denmark.

More on study groups at:

Welcome! Groups are open for all HPs if not indicated otherwise.

<table>
<thead>
<tr>
<th>Meeting Title</th>
<th>Date</th>
<th>Start</th>
<th>End</th>
<th>Room</th>
<th>leader/host</th>
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<tr>
<td>HP Psychologist Study Group</td>
<td>Thursday 12.06.2014</td>
<td>17:00</td>
<td>18:00</td>
<td>Sisley</td>
<td>Erik Taal <a href="mailto:e.taal@utwente.nl">e.taal@utwente.nl</a></td>
</tr>
<tr>
<td>HP Occupational therapist Study Group</td>
<td>Thursday 12.06.2014</td>
<td>18:00</td>
<td>19:00</td>
<td>Sisley</td>
<td>Yeliz Prior <a href="mailto:y.prior@salford.ac.uk">y.prior@salford.ac.uk</a></td>
</tr>
<tr>
<td>HP Foot &amp; ankle study group meeting</td>
<td>Thursday 12.06.2014</td>
<td>18:00</td>
<td>19:00</td>
<td>Matisse/Renoir</td>
<td>Anthony Redmond <a href="mailto:A.Redmond@leeds.ac.uk">A.Redmond@leeds.ac.uk</a></td>
</tr>
<tr>
<td>HP Nurses Study group/Clinical</td>
<td>Friday 13.06.2014</td>
<td>08:00</td>
<td>09:00</td>
<td>Dufy</td>
<td>Jenny de la Torre-Aboki <a href="mailto:Delatorre_jen@gva.es">Delatorre_jen@gva.es</a></td>
</tr>
<tr>
<td>HP Physiotherapist Study Group</td>
<td>Friday 13.06.2014</td>
<td>08:00</td>
<td>09:00</td>
<td>Sisley</td>
<td>Rikke Helene Moe <a href="mailto:rikmoe@gmail.com">rikmoe@gmail.com</a></td>
</tr>
<tr>
<td>HP Nurses and Strategy Group</td>
<td>Friday 13.06.2014</td>
<td>09:00</td>
<td>10:00</td>
<td>Dufy</td>
<td>Yvonne van Eijk-Hustings <a href="mailto:yvonne.eijk.hustings@mumc.nl">yvonne.eijk.hustings@mumc.nl</a></td>
</tr>
</tbody>
</table>
Dear colleagues and friends, I am retiring from my position within the Czech Health Professionals (CAZR) and also from the EULAR HP Committee. Before I leave, I would like to share a few memories from my time at EULAR with you and how it has influenced the Czech HP history.

Over the period of 19 years, many things have occurred. I first came to a EULAR congress in 1995 in Amsterdam. At that time, I had just a short work experience and I still was not entirely sure that rheumatology was the best choice for me. The professional and public awareness of rheumatology branch was limited, and rheumatology nursing – even within EULAR – practically did not exist.

At the congress, my enthusiasm was overwhelming because I met a large number of awesome, friendly people and gained a lot of information about people with arthritis, their problems and needs. I learnt a great deal about rheumatology that later turned out to be crucial for my future decision to continue in this field and later in EULAR.

At the end of the 20th century, EULAR started to organize Annual Congresses. Almost at the same time, a new EULAR Standing Committee of Health Professionals in Rheumatology was established. In 2001, EULAR Annual Congress took place in Prague and I was much involved in its organization. I was very happy that I could actively participate in this process of promoting HP work.

The fruits of EULAR
Concurrently with the beginning of the EULAR HP Committee, we established together with colleagues a group of the Czech Allied health professionals working in rheumatology. At that time, our activities were closely connected with medical doctors, rheumatologists, and the Czech Rheumatology Association (CRS).

In accordance to the Bone and joint Decade initiative, later also in compliance with Alliance against Arthritis, we tried to promote rheumatology through the media and the scientific community. Besides, we prepared a huge number of educational events for HPs and for people with arthritis and we also addressed high schools for nurses, universities, and institutions for the health professionals so that they would give more visibility for studies in rheumatology.

I have to emphasize the importance of our cooperation with the Czech Rheumatology Association (CRS). Our connection to the CRS perceived extremely important, as it meant we could contact the Czech rheumatologists, their nurses and other allied health professionals. The Czech rheumatologists supported our work and all initiatives very much, also financially.

After organizing the first EULAR AHP educational visit in Brno (1998) in the Czech Republic, we published the second part of the "mini" textbook of rheumatology. It was a sort of educational starting point for Czech health professionals as our HP students used these textbooks. Ten years later, in 2008, three Czech HPs participated in the EULAR Teacher Course (TtT course) in Leiden and only one year later we brought the TtT course to Brno. It was a very successful course and it produced a further course of rheumatology care in the Czech Republic.

What we have managed so far?
Over the past 19 years of intensive work, we have achieved a number of successes – yet, there were also failures that we had to face. I mention this because if you decide to build something new you always should be prepared for setbacks, no matter who you are and how much experience you have. When we started, we had no experience at all. Today, I can say that it is extremely important to have sufficient amount of

Jana Korandová worked as EULAR’s HP Vice-president during the years 2000–2002 and as the president of the Czech Health Professionals (CAZR) starting 2011.
motivation but also the right individuals who have similar goals, motivation, and stamina to continue even when there are setbacks to get by.

Nowadays, the HPs know more about rheumatology and so do lay people. In 2012, the first rheumatology module in the specialization course for nurse specialist in internal medicine was included in the Czech Republic. By the end of this year, eight modules of rheumatology will be a reality at the National Centre for the Further Education of Health professionals in Brno and another, similar module will begin at the Centre of Education in Thomayer’s hospital in Prague. That means more than 300 students will be trained in rheumatology. The rheumatology module was created on basis of the Teach the Teachers Course program.

In 2011, we released a Czech lexicon of Rheumatology for health professionals. It is a sort of “pocket version” of rheumatology handbook. Just a tiny textbook, but it works. By the end of 2013, our Institute of Rheumatology gained accreditation called the Certificate of Quality and Safety. It is a very important certificate for us as it means we seem to be doing our work well.

Likewise, we participated in the drafting of EULAR recommendations for the role of the nurse in the management of chronic inflammatory arthritis. Currently, some of us try to put them into practice in the Czech Republic. We also cooperate within the Task Force group – the project EULAR points to consider for patient education of people with inflammatory arthritis.

Face a major challenge and saying goodbye
Despite number of successes we still, however, face a major challenge – both to increase number of active members but also how to motivate them. One of the possible reasons for why our CAZR organisation sort of stands still might be that the workplaces and units with whom we long cooperated with have changed their focus and many of the health professionals have left their workplace and they no longer work in the field of rheumatology. We are very sorry for this and changing the negative situation is one of our main tasks and objectives for the future years.

I would like to thank all my friends and/ or colleagues for their hard work and at the same time I wish you a lot of success in your personal and professional life. I will no more represent the Czech Health Professionals in Rheumatology within EULAR but I am ready to cooperate with EULAR and you all in case my assistance, experience or whatever else would help.

There are many people who helped me to understand what EULAR is all about, for instance Dr. Bruno Albada, Marjan Hjudomalj, Sophie Edwards, Birte Glusing, Neil Betteridge, Jackie Hill, Anne Boss, Ulla Nordenskjöld, Nora Price, Jaana Hirvonen, Sue Oliver, Yvonne Hastings, Fred Wyss and later all the new EULAR Secretariat employees and many, many others – sorry I can’t mention all as it would be a long, long list of names.

Jana Korondova

Read also Ulla Nordenskjöld’s historical HP perspective at http://www.eular.org/myUploadData/files/HPR%20history.pdf

“A team building exercise in the Czech way. EULAR Teach-The-Teacher courses participants in 2009 were asked to prepare a fashion show using plastic bags.

“EULAR had the essential impact on the birth of the Czech rheumatology nursing and on the creation of educational programs aimed at the non-physicians working with people with arthritis.”
The European Project for Rare Diseases

In ideal circumstances, these initiatives on equal care will be integrated at local, regional, and national levels for a comprehensive approach and if needed also cross border healthcare should be considered. Also priority actions with objectives and follow-up mechanisms need to be defined. Despite the progress made over the last years in the field of rare diseases, a comprehensive and evidence based approach is still missing in many EU Member States. This leads to an incomplete and often inadequate framework to address RD. The project aims to develop recommendations on how to define strategic plans for RD. Such recommendations will include best practices to address RD and information on the different steps to develop a plan. This will support the harmonisation of public health strategies on RD throughout Europe.

Is your country included?
Norway has had recommendations on RD since the nineties. For instance Austria, Belgium, Bulgaria, Cyprus, Czech Republic, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Luxembourg, Portugal, Romania, Slovak Republic, Slovenia, Spain, The Netherlands and United Kingdom have adopted plans or strategies on Rare Diseases. Some of the countries have just finished the process of the national strategy, for example Finland, and some of the countries, for instance France, have already an updated version in use. Other EU countries are about to launch their strategies as well.

Do you know if your country already has a national strategy for rare diseases? Has it changed the diagnostic protocol or care of the patients with rheumatic diseases?

The 3rd Nordic conference on rare diseases September 4-5, 2014 will be held in Helsinki. The NCRD 2014 conference is organised by the Finnish Network for Rare Diseases and the Nordic Rarelink Group together with the Ministry of Social Affairs and Health in Finland. The highlights and challenges of national plans and strategies for rare diseases of Nordic Countries will be introduced in the conference.

Further information:
The European Project for Rare Diseases National Plans Development (EUROPLAN): http://www.europlanproject.eu/_newsite_986989/index.html

There is a number of rare rheumatic diseases such as

- rare connective tissue diseases:
  - Ehlers-Danlos syndrome
  - SLE/Lupus
  - Mixed Connective Tissue Disease (MCTD)
  - Systemic sclerosis or systemic scleroderma

and many rare vasculitis
People with RMDs and health professionals
Working in Partnership

Over our lifetime, we develop a wide range of partnerships. For people with rheumatic and musculoskeletal diseases (RMDs), I believe that one of the most important and an influential connection is with health professionals. Complex and chronic conditions require a network of support and interventions from a wide variety of healthcare specialists. Each has particular expertise, and they all work for the best possible outcomes for patients, offering vital support, treatment, and advice when needed.

HP expertise in programmes
The Standing Committee of People with Arthritis/Rheumatism in Europe (PARE) and the Standing Committee of Health Professionals in Rheumatology have an exemplary track-record of working successfully in partnership. PARE strives always to incorporate the views and expertise of health professionals in its projects and programmes. I am immensely grateful to Susan Oliver, Thea Vliet Vlieland, Christina Opava and Annette Ladefoged de Thurah for their enthusiastic and unstinting support.

In 2013 and 2014, the Standing Committees of PARE and the Standing Committee of Health Professionals in Rheumatology worked very closely together to deliver an exciting range of information and advice on the World Arthritis Day theme "Living Better Ageing Well". The topics included physical activity and exercise, healthy eating, emotional well-being, and self-management and motivation. The collaboration involved physiotherapists, nutritionists, behavioural psychologists, occupational therapists and many others. The resulting educational material is now widely available on the World Arthritis Day website –www.worldarthritisday.org – for the benefit of people with RMDs across Europe.

‘Take control of your life’
In 2015, the Standing Committee of PARE’s theme will be ‘Take control of your life’. This will not only focus on patient self-management strategies and how to achieve personal goals, but also explore how patients and health professionals work together, and share decision-making, in order to achieve better outcomes. Empowering and educating people with RMDs enables them to be involved actively in their healthcare and treatment choices and gives them the confidence and skills to make positive lifestyle decisions. PARE will be asking people with RMDs to share their experiences of innovative and new ways in which they are working constructively with their health professionals, both individually and as part of multidisciplinary rheumatology teams. I expect to see some exciting examples of best practice emerging. I hope too that many national PARE organisations will take the opportunity to form or renew close partnerships with their national health professional organisations.

“Alone we can do so little; together we can do so much”
Helen Keller

Di Skingle
Chair of the Standing Committee of PARE

PARE will be asking people with RMDs to share their experiences of innovative and new ways in which they are working constructively with their health professionals.
eHealth program of the Arthritis Centre in Twente

EULAR-funded educational visit to the Netherlands 9-12 October 2013

After a busy working day in Bern, Switzerland, I started my trip to the Netherlands where I arrived in Amsterdam late in the evening of October 9th 2013. Early next morning my train left to Enschede because I wanted to join Jolanda Schoemaker-Delsing at the Arthritis Centre of Twente/Enschede where she is running her outpatient clinic. Jolanda is working as an Advanced Practice Nurse (APN) in Rheumatology for which a Master’s Degree and a specialisation in the field of Rheumatology is required.

The aim of my educational visit was to acquire information about the development of the eHealth program of the Arthritis Centre in Twente and to achieve insight into the daily clinical care. Furthermore, I was keen to learn more about the work of APNs in Rheumatology, about their job descriptions and the clinical benefit of their roles, while identifying gaps in the patient-centred care for the development of my role as an APN and the patient education offered at the Department of Rheumatology, Inselspital, Bern University Hospital in Switzerland. According to my knowledge, so far there is no other APN in Rheumatology in Switzerland.

eHealth at the Arthritis Centre of Twente

Clinicians of the Arthritis Centre and scientists of the University of Twente developed together with health care professionals and patients a website with an Interactive Health Communication Application (IHCA) with the aim to improve patients’ disease management. Patients were asked before the start of development of the website to comment about their general Internet use and specifically about their health and rheumatic related Internet access. They were also asked about their needs for the IHCA, their motives for using the Internet, and their preferences for the usage of the applications (van der Vaart et al., 2011). Van der Vaart et al. (2011) found out that most patients with Internet access had used the Internet in relation to their disease (82%), mainly to search for disease specific information. The study showed also that participant’s intention to use the IHCA was high. Patients preferred to obtain online information on medical and support topics and were interested in communicating online with their physician.

The IHCA contains information on pathophysiology and therapies (“Reuma en behandeling”), and information about the arthritis clinic (“ReumaCentrum Twente”). Besides information it also contains a peer support group service (“Patiënten voor patiënten”). In addition, they have the possibility to login into their personal medical records (“Mijn reumaportaal”), here patients can also monitor their health-related quality of life (SF36) and their physical health (HAQ) by viewing their scores over time.

Comparable to the Swiss Clinical Quality Management in Rheumatic Diseases (SCQM, http://www.scqm.ch) database, the patients fill in the online questionnaires on their state of health (Health Assessment Questionnaire, HAQ), health-related quality of life (SF-36) and disease activity (DAS28) before seeing the rheumatologist. In addition, the patients are able to see their current medication but also a chart that shows the correlation between the treatment modifications and their disease activity. During the consultation, the rheumatologist discusses the laboratory results with the patient. Back home he can see the results in his personal medical records on the IHCA.

One important outcome of this project between the University and the hospital was that the care providers did not want to publish all parts of their medical record on the patient portal (van der Vaart, Drossaert, Taal, et al., 2013). For the patients, it was sometimes difficult to interpret laboratory results and compare them with previous values (van der Vaart, Drossaert, de Heus, et al., 2013). The results also demonstrate patients’ lack of skills in searching for reliable information on the Internet. Many patients struggled with defining appropriate search strategies and evaluating the information found caused problems. This is worrisome, since previous studies showed that many rheumatology-related websites provide unreliable information (Ansani et al., 2005).

Thus, patients’ accessible records have to be clear and limited to the essence so they can understand it. The patients of the Arthritis Centre Twente only can see limited laboratory results (Hb, CRP, ESR). When developing a new website or IHCA it is important to pay attention to the adaptation of the level to patients’ skills (eHealth...
Implementing a new APN role – other country, same challenges

Jolanda Schoemaker-Delsing received her Master’s Degree six years ago, during her studies she was working for three years at the outpatients’ clinic, supervised very closely by a medical doctor while specializing in the physical assessment and implementing her role. First, she took responsibility of patients with gout and she wrote a protocol to standardize care. Within that protocol, Jolanda is authorized to prescribe medication. After that first step, Jolanda further expanded her role; today she sees newly diagnosed patients with other rheumatic diseases, such as patients with Rheumatoid Arthritis or Ankylosing spondylitis. Jolanda told me that there are about 25 Rheumatology APNs in the Netherlands. She closely cooperates with them in the development of care protocols and they are organizing their own education to get credits to maintain their accreditation.

Jolanda’s experiences encouraged me to improve my expert knowledge in SSc and to write a standard operating procedure for the specialized care and the nurses’ role. Within the scope of standardizing care, all SSc patients should see an APN when attending the clinic. SSc patients from our clinic described variable diagnostic experiences, and receiving poor, or incomprehensible, information on disease pathology at the time of diagnosis (Kocher et al., 2013). Consistent with the findings of van der Vaart et al. (2012), they had started to perform their own Internet research (van der Vaart et al., 2012). However, in many cases this did not make the diagnosis more intelligible for them, and even generated more questions. This is why an APN should provide patients and families with timely, understandable information on SSc pathophysiology and symptoms and training them in seeking trustworthy sources of disease information.

Furthermore, my role could be expanded with a new patient group. As Jolanda did, it could be a less complicated diagnosis group as the gout patients are, where a nurse-led intervention including education, lifestyle advice and urate-lowering therapy can successfully achieve the recommended treatment target in more than 9 out of 10 patients (Rees et al., 2013). But to date in Switzerland’s tertiary hospitals the drivers to get nurses in such substitute roles are not that strong. Most APNs are working in complementary roles, which means that their work is adding a service to standard care instead of replacing a medical doctor by a nurse. Thus, I think there is a need to improve care for patients with rare rheumatic diseases because there is little special attention for this patient group: Information materials and patient organisations are as rare as the diseases themselves.

Besides Jolanda, I was able to meet another APN, Nancy Schotmeijer. She also works at the outpatients’ clinic of the Arthritis Centre Twente and in her holidays she bikes together with arthritis patients and health professionals to the EULAR congress. This is her contribution to reduce cardiovascular risks in people with rheumatic diseases (http://www.reumarat.nl/).

After the educational visit, I had the great opportunity to attend the first international conference for rheumatology nurses in Rotterdam where I met many rheumatology nurses and researchers, whose names were only familiar to me through their publications. Meeting all those experts involved in the same field gave me the trust that I can count on APNs in rheumatology from all over Europe for advice and support any time.

See you at the EULAR congress in Paris – by bike!

Agnes Kocher
Advanced Practice Nurse, MScN
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Read more about how to apply an educational visit grant on page 18.
Our U.S. colleagues from the Association of Rheumatology Health Professionals (ARHP) will be joining us in Paris for the EULAR Congress. ARHP has kindly offered to share some of the HP articles published earlier at the Rheumatologist journal. We chose the following articles about medication quick guides and about the impact of nutrition on the care of RMD. Enjoy!

ARHP president Karen Smarr, PhD will participate in EULAR Congress with ARHP immediate past president Jan Richardson, PT, PhD, OCS, ARHP president-elect Kamala Nola, PharmD, MS, ARHP past president Linda Ehrlich-Jones, PhD, RN, and ARHP past president Benjamin Smith, PA-C. More on ARHP Executive Committee at http://www.rheumatology.org/about/leadership/ARHPExecutiveCommittee.asp

Medication Quick Guides Offer Infusion Staff a Streamlined Resource

Infusion personnel now have a new resource for medication administration. With recent advances in medication for the treatment of rheumatic diseases, osteoporosis, and gout, management of different administration protocols is more complicated. To ensure proper administration and patient safety, quick-reference information can be a useful tool for infusion personnel.

The ARHP addressed this need by developing online Medication Quick Guides for access by members via the ACR/ARHP website. The Quick Guides have been completed for many medications, including biologic disease-modifying antirheumatic drugs, antiresorptive medications, and other medications administered in intravenous and injectable dosage forms.

Infusion staff already familiar with the medications can be aided by the streamlined information provided by the Quick Guides. Each Guide is labeled with the last date of review and includes a link to the manufacturers’ full prescribing information, patient medication guide, and applicable dosing calculators. In the future, a patient financial resource link for the medications will also be provided. This will allow infusion personnel ready access to information regarding financial assistance resources for their patients.

Information for the Quick Guides was obtained from the manufacturer’s full prescribing information and the ACR Model Biologics Policy. This policy is available to members on the ACR website. The Model Biologics Policy includes information on a medication’s FDA indications, dosage information, biologic molecule description, and off-label use with references.

The Quick Guides provide an ACR/ARHP members-only benefit of free access to streamlined information regarding the administration of biologic, antiresorptive, and other medications used to treat patients with rheumatic disease. Additional Medication Quick Guides are being developed by the ARHP Practice Committee.

Inquiries or suggestions regarding development of new tools or references relative to rheumatology practice for the ARHP Practice Committee consideration may be forwarded to arhp@rheumatology.org.

Susan Richmond, MS, PA-C; Karla B. Jones, RN, MS, CPNP

Susan Richmond is assistant professor in the School of Physician Assistant Studies at the Massachusetts College of Pharmacy and Health Sciences in Boston. Karla Jones is a pediatric nurse practitioner at Children’s Hospital in Columbus, Ohio.

This article has been earlier published in: The Rheumatologist, June 2012
The Dietitian’s Role in Managing Rheumatology Patients

Registered dietitians can help patients make the changes needed for good health. “Do I need to be on a special diet?” Those who care for rheumatology patients field this question every day. Many rheumatology patients think that what they eat will affect the course of their disease and their symptoms. In search of a diet prescription, rheumatology patients obtain nutritional information from a variety of sources. Some hear anecdotes from family members or friends regarding what they should or shouldn’t eat to treat their condition. There is also an abundance of information (and misinformation) circulating in the media related to the impact of nutrition on rheumatoid arthritis (RA) and lupus.

Although resources on diet and disease management are widely available to patients with rheumatic diseases, not all the sources of this information can be trusted. Furthermore, it can be daunting for patients to read about nutritional “arthritic cures” or “anti-inflammatory diets” when they must deal with pain and fatigue symptom in addition to managing their medication regimens.

How can patients filter which information is credible and which dietary advice is false? What support can be given to patients who may want to seek out nutritional guidance from experts? Registered dietitians can be valuable team members, and help properly educate patients with rheumatic conditions on the role of nutrition and their health.

As a registered dietitian, I have often been asked by patients with RA whether they should or shouldn’t eat to treat their condition. Questions about the use of supplements or dietary practices to their medical providers. Dietary counseling by a registered dietitian is an important treatment modality to help provide clarity and evidenced-based facts on the effectiveness of nutritional claims related to rheumatic diseases.

The Dietitian’s Role in Managing Rheumatology Patients

When dietitians consult with patients who inquire about dietary claims and supplements, they often review the evidence and safety concerns related to the claims. In addition, they evaluate patients’ eating styles to ensure that individual nutritional requirements are met in order to prevent nutrient deficiencies. Nutrition consultations for rheumatology patients also include education on balanced diets and addressing health risks associated with rheumatic diseases.

Although there is no evidence to support most of the dietary claims out there, such as avoiding nightshade vegetables or following elimination diets, there is some support to promote the Mediterranean diet, consuming omega-3 fatty acids, and vegetarian diets. Rheumatic diseases are risk factors for cardiovascular disease and osteoporosis. Obesity, hypertension, and kidney disease are also concerns for rheumatology patients. Patients who present with these additional health risks should be guided on heart-healthy diets and weight-management guidelines, and counseled on adequate calcium and vitamin D intake.

Registered dietitians can educate patients on these guidelines, and can help patients make the necessary lifestyle and behavior changes needed for increased adherence to nutritional guidelines and overall good health.

Sotiria Everett, EdD, RD, CDN, CSSD

Sotiria Everett is a clinical nutritionist at the Hospital for Special Surgery in New York City. She studied Nutrition and Applied Physiology at Teachers College at Columbia University.

References

1. Ikuyama S, Imamura-Takase E, Takanaga S, Oishi M, Kishimoto J. Sixty percent of patients with rheumatoid arthritis in Japan have used dietary supplements or health foods. Mod Rheumatol. 2009;19:253-259.

This article has been earlier published in: The Rheumatologist, November 2013

During the Bone and Joint Decade (BJD) in Finland a popular cartoon figure called Mauno Mansikka tried to promote healthy eating and weight-management. Picture by Jorma Pitkänen
HP Chair Sue Oliver welcomes new national HP organisations to become members of EULAR

EULAR seeks national HP organisations to become members of EULAR and participate in the work of the EULAR HP Committee. All interdisciplinary health professional organisations specialised in the care and treatment of rheumatic and musculoskeletal diseases in European countries are welcome to join in.

– We managed to secure a small fund to enable us to visit countries that are seeking guidance in preparing their member submission. You can contact me for more details, HP Chair Sue Oliver points out.

For the moment EULAR has seventeen actual HP member associations. There are more to come. For instance Israel is applying for membership at the General Assembly in Paris 2014 and other associations are preparing for becoming members in the near future.

– The more members we have for HPs the more we have a vote, ability to build and strengthen the input of HPs in congress and across all EULAR initiatives. It also gives all of us a greater vision of what is really needed across the whole of Europe in terms of HP development and improvements in patient care, Oliver says.

Planning to become a member?

Please get acquainted with the 5-step plan on how to establish a national HP society and become involved with EULAR. Contact us for further information.

1. If a national interdisciplinary health professional organisation already exists in your country, please find out first whether this organisation has a guest representative in the Standing Committee of HPs. If so, please contact this person regarding your involvement in EULAR.

2. In case there is no organisation representing health professionals in your country, you can establish a national organisation first. Bear in mind that this organisation’s bylaws should be in accordance with the EULAR bylaws. You can obtain the bylaws from the EULAR Executive Secretariat, contact: eular@eular.org.

   Importantly, this national organisation should represent different health professional groups (such as nurses, occupational therapists, physiotherapists, podiatrists, nutritionists, social workers, psychologists, and others) and should have a clear multi-/interdisciplinary perspective.

   All the professional groups mentioned above do not have to be represented in the organisation, but an open attitude towards all health professionals in the organisation is required.

3. Fill in the application form which you can also obtain from the Secretariat together with a letter stating that your organisation wants to join EULAR as a health professional organisation representing your country. Submit this application form to the EULAR Secretariat. The General Assembly meeting, held once a year before the annual EULAR Congress, will put your application and acceptance within EULAR to the vote.

4. When your organisation is a formal member, the person representing this organisation will also have a right to vote in the General Assembly.

5. The president of the national organisation will usually represent the organisation as delegate in the EULAR Standing Committee of HPs.

   In the process of establishing a national organisation and even before this, the Committee welcomes any health professionals interested in founding a national organisation to become a guest representative in the EULAR Standing Committee of HPs. As a guest representative you are then welcome to participate in the meetings of the Committee and in other activities within EULAR. In this case, please contact the Chairperson of the Committee, Sue Oliver: sue@susanoliver.com

   More information available at: www.eular.org/st_com_health_professionals.cfm

JOIN IN!

EULAR Health Professionals News 16
The EULAR HP member directory

The HP committee will publish an online HP member directory, which will provide information on national HP member associations, their main functions, interdisciplinary broadness and contact information. On this page we have used, Cosmosrheuma+, the HP association from Cyprus as an example on what the member presentation could look like in the directory.

Health professionals in Cyprus - Cosmosrheuma+

Secretary Office
Cosmosrheuma+
Onisilou 16, Apartment 1, Aglantzia
2121 Nicosia, Cyprus

President
Mr. Costas Ioulianos
lampadistis@hotmail.com

Treasurer
Mr. Leandros Iakovou

General Secretary
Ms. Maria Psilolychnou

Liaison Officer with EULAR
Mr. Costas Ioulianos
Further contact person
Maria Psilolychnou Nedyfou
mariapsneo@yahoo.com

About the organisation
The association was founded in 2012 and became a member of EULAR in 2013.

Website:
Under construction

The aims of the organisation are:
Cosmosrheuma+ aims to empower health professionals specialised in rheumatic diseases. To cooperate and gain benefits from the interdisciplinary know how, and make use of the latest European recommendations for optimum care.

Main events:
The association organises annual assembly meetings. It is represented in EULAR congresses and takes part in the celebration of the world rheumatism day with the local patient organisation.
The main achievement, however, is the formation of an interdisciplinary team that travels around the island, visiting difficult in access locations, screening, treating and educating people about rheumatic and musculoskeletal diseases. Finally, various seminars have been on the association’s agenda, with the hydrotherapy seminar for physiotherapists, coming first.
A multiprofessional symposium is to be organised within 2014.

HP member structure

<table>
<thead>
<tr>
<th>Number of members</th>
<th>92</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health professional disciplines presented (percent or number)</td>
<td></td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>36 %</td>
</tr>
<tr>
<td>Podiatrists</td>
<td>24 %</td>
</tr>
<tr>
<td>Nurses</td>
<td>18 %</td>
</tr>
<tr>
<td>Occupational therapists</td>
<td>1 %</td>
</tr>
<tr>
<td>Psychologists</td>
<td>2 %</td>
</tr>
<tr>
<td>Social workers</td>
<td>3 %</td>
</tr>
<tr>
<td>Nutritionists</td>
<td>2 %</td>
</tr>
<tr>
<td>General Practitioners</td>
<td>1 %</td>
</tr>
<tr>
<td>Pharmacists</td>
<td>-</td>
</tr>
<tr>
<td>Rheumatologist representative</td>
<td>-</td>
</tr>
<tr>
<td>Patient representative</td>
<td>-</td>
</tr>
</tbody>
</table>

Other professionals/representatives, which:
Speech therapists: 4 %
Psychotherapist: 1 %

President of the association
Mr. Costas Ioulianos is a physiotherapist by profession.
EULAR awards up to 10 bursaries for educational visits to health professionals other than physicians working in the field of rheumatology. The objective is to improve the standard of research and care in health professions and to foster collaboration across clinical units in Europe.

Bursaries will not be granted to applicants who are already abroad in a visiting programme. The amount of each bursary is between EUR 750 and 1,500 (the annual total amount granted is EUR 7,500). Applications should be submitted by e-mail to the EULAR Secretariat at gabriela.kluge@eular.org.

Recipients are required to submit a report (maximum 1 page) to the EULAR Secretariat after the stay, focusing on the results that have been achieved.

The form is available at http://www.eular.org/health_professionals_educational_visits.cfm

Apply for an Educational visit grant

EULAR’s Education Programme Coordinator Gabriela Kluge is happy to assist you when planning an HP educational visit.

Evaluation criteria for research projects
• Project leader should be a health professional
• Involvement of at least three European countries
• Scientific value
• Implementation and relevance for EULAR Health Professionals (i.e., how the project may improve the non-pharmacological management of patients in a short and/or long-term perspective, and/or whether the project may foster the development of a research network of relevance for the future beyond the period of the project)
• Quality of the work plan and methods
• Feasibility of the study within the planned timeframe
• Patient centred approach (if applicable, please specify the following):
  • Describe patient involvement in the design of the study
  • Describe the patient specific outcome measures
• Budget realistic for the planned project
• Planned dissemination and implementation of the research results

Application deadlines for Educational visit grants are 31 March and 30 September each year.

Applications should include:
• Curriculum vitae with date of birth
• Objective of the educational visit
• Budget
• Written confirmation from the host hospital or institute that the educational visit has been accepted, indicating the tentative time frame of the training stay.

Applicants also need to sign an application form and contract. The form is available at http://www.eular.org/health_professionals_educational_visits.cfm
The next EULAR Annual European Congress of Rheumatology will take place from 10-13 June 2015 in Rome, Italy. The annual EULAR congress is now a major event in rheumatology. As have previous congresses during the last decade, EULAR 2015 in Rome will provide a unique event for the exchange of scientific and clinical information.

The official Congress Website will be available mid July 2014.

Abstract submission

The electronic abstract submission system will be open until the 31 January 2015.

Abstracts received after the deadline will not be accepted. Health professionals (HP) can choose to submit their abstract either for practice and clinical care (HP topics A5) or for clinical research work (topics 11-34).

Please note that when submitting to topics 11-34, your work will be scored by rheumatologists, whereas the HP topics A1-A5 are scored by health professionals.

Further information will be made available from August 2014 on the EULAR website www.eular.org.

The HP program of the EULAR Congress

The EULAR Congress 2014 in Paris will be the venue of high-quality HP scientific sessions introducing health professional research and issues of interest in the HP practice. There will be HP sessions, two abstract sessions, and poster tours. In addition, there will be a highlight session and joint sessions organised together with rheumatologists and the Standing Committee of People with Arthritis/Rheumatism in Europe (PARE).

The full program is available at EULAR website: www.eular.org.

**HP Session topics**
- The Scleroderma Patient-centred Intervention Network (SPIN): Meeting the challenges of non-pharmacological research into a rare disease
- Targets and mechanisms of treatment in chronic pain
- eHealth literacy on rheumatic diseases – analysing the power of the Internet
- Practical implementation of annual reviews in patients with inflammatory arthritis – sharing experiences
- Promoting a healthy lifestyle among patients with arthritis – how are health professionals doing?
- Is it a flare? Focus on patient self reported disease activity measures in RA.
- Health Professionals & ultrasound. How to implement imaging into clinical practice.
- Highlights from EULAR 2014. What’s new? The key take-home message from PARE, Rheumatologists and HPs

**Abstract sessions I and II**

**Joint Sessions**
- Patients’ perspectives in rheumatologic outcomes
- Patient education for people with inflammatory rheumatic diseases
At the moment, seventeen EULAR HP member organisations are represented by their presidents or other nominated officials at the EULAR Standing Committee of Health Professionals in Rheumatology (the HP Committee). The HP delegates contribute to shaping health professionals activities within EULAR. The Committee, headed by Chair Sue Oliver and Vice President Christina H. Opava, discusses the on-going projects and new proposals to the EULAR Executive Committee, initiates for the health professionals’ program at the next congress, and reviews HP membership applications. Each year, the Committee holds its annual meetings on the EULAR congress. The Committee has two sub-committees and can also include other invited experts.